

ARIZONA DEPARTMENT OF HEALTH SERVICES
OFFICE FOR CHILDREN WITH SPECIAL HEALTH CARE NEEDS

**ORGANIZATIONAL STEPS TO CREATE
PARENT-LED COMMUNITY DEVELOPMENT**

Promoting Community Change for Children with Special Health Care Needs

**Step 1: IDENTIFY AND/OR DEVELOP
COMMUNITY GROUP OF INVESTORS/STAKEHOLDERS**

Communities may enter the process either through invitation or self-selection. It's important to be "invited into" the community by respected community leaders; it provides a sense of legitimacy and importance. Meet with the leaders and explain the mission. Get to know the community, its strengths, sources of pride, history and ways of communication. Seek out parents of children with special needs to serve as guides and facilitators. Meet with groups of parents, explain the mission and determine their interest in forming an action team to address issues within the community. If interested, contract with two or three to serve as leaders, developers and facilitators.

Determine if there is an existing action group, or if a new group is to be formed. Seek out individuals from public health, medical, education, social service sectors and community citizens such as elected officials, city, business and faith people and other leaders. Parent Leaders invite professionals to join them in their community development work, and obtain a sense of interest and commitment. Always ask, "Who else should we be talking to?" and "What else do we need to know?"

Step 2: CONDUCT COMMUNITY ASSESSMENT

Conducting a community assessment assists in identifying resources, skills, issues and trends. It is a helpful organizational process that directs the team's attention to a collaborative, learning effort. The information gathered also provides legitimacy to the effort.

The community action team, facilitated by the Parent Leaders, plans the assessment. Parent and professional forums are held, team members conduct key informant interviews and family surveys are completed. Forums and interviews examine availability, accessibility, affordability, quality and coordination of services provided to children with special health care needs and their families. Community resources, skills, talents, relationships and institutions are identified. Conversations are recorded for analysis, with participant permission.

Step 3: DATA ANALYSIS/REPORT CARD

Interview and forum responses are transcribed, compiled and organized. Survey data is entered into a database for analysis. Community team members and staff analyze the information together and design the format for a Report Card. The purpose of this report

is to describe and examine both the community and its system of care for children with special health care needs and their families.

Step 4: *COMMUNITY PRESENTATION OF COMMUNITY ASSESSMENT RESULTS*

Community team members plan and present the Report Card and the assessment results to the community through various methods, such as a large community gathering, small presentations to city councils and school boards, distribution of report cards and newspaper articles. Presentations include discussion of findings, confirmation of resources, a sense of priorities, a call and commitment to action and decision-making for next steps. Parent Leaders and team members identify who, when and where dissemination occurs.

Step 5: *COMMUNITY ACTION*

Community presentations help to give a sense of priority, as participants vote on issues of concern to them. Parents are given a weighted “vote.” Community team members consider the outcome and select an initial issue, not necessarily the most important issue, but one that is most interesting and that people are motivated to address. As an issue is resolved, the team prioritizes and resolves additional family and community issues.

Step 6: *ONGOING COMMUNITY SUPPORT/INCREASING LEADERSHIP/ LINKING OF COMMUNITIES*

On-going technical assistance and support needs to be provided to the Parent Leaders and Community Action Teams. Parent Leaders are reimbursed for the time spent in leadership activities, monthly conference calls and meetings with other Parent Leaders and staff and a biennial conference that enables team members from all teams to learn community development strategies, together. Work is centered around the continuous development of new leadership, increasing skills and building relationships. Communities link with one another and mentor each other, sharing ideas and experiences.

Step 7: *MEASURING SUCCESS*

Success is measured with an on-going gathering of data (Catalogs of Progress) that documents not the action taken but the reaction received. Three areas are addressed:

- 1) Operating system of public health, medical, social services and education services;
- 2) Community, which includes measures of community compassion, satisfaction and participation; and
- 3) Team Change Effort, which addresses organizational functioning, membership, marketing and resources.

Community Development requires a patient, persistent, deliberate approach to promoting change, and calls for mutual learning, relationship building and respect for community ownership of issues and actions. Community Development produces self-reliant communities that mobilize resources to benefit all their members. Parent/professional partnerships are the key to the Community Development process, both at the community and state levels. State level support of community initiatives includes identification of resources and remediation of barriers. Success within communities translates to success at the state level.

Communities and participants of the system are positively influenced and altered through exposure to the principles and practices of Community Development, parent leadership and parent/professional partnerships. Communities play greater roles in resource allocation and setting of policy. Professionals see families move from recipients of service to self-reliant developers. Awareness of children with special health care needs is increased in communities and results in all children being appreciated and valued.